

## **HISPANICS AND ORGAN DONATION: PROSPECTS, OBSTACLES AND RECOMMENDATIONS**

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### **Summary of Main Points**

Hispanics are a large and rapidly growing group with several unique characteristics relevant to health planners and policy makers.

Hispanics are an aggregation of different national origin subgroups with different biological and historical backgrounds and different geographic distributions. Any generalization about Hispanics should be checked to see that it applies across all of the different Hispanic subgroups. The same is true regarding immigrant status, language dominance, and class status.

A few States and several cities contain much of the U.S. Hispanic population.

Latinos are generally younger, poorer, and less well educated than the general population.

There are at least three major segments of Latinos: Spanish-dominant immigrants, English-dominant or bilingual lower class natives, and the English-dominant middle class.

Mexican Americans have a much higher incidence of ESRD than the general population. The incidence of ESRD among non-Mexican Latinos is not known.

The proportion of Hispanics receiving transplants is similar to the proportion on the waiting list.

Hispanics do not have equal access to health care because of cost, language, and lack of insurance coverage.

The strongest objections Hispanics have to organ donation seem to come from lack of access to health care.

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The method of approaching the next of kin for permission to remove organs for donation can be made sensitive to Hispanic needs and concerns.

Family-oriented Spanish language television might be a good way to raise the issue of organ donation in a context where potential donors could express their sentiments to their family members.

A Hispanic-specific program could and should have a goal of general equity of organ donation and transplantation.

### **Introduction**

Hispanics are one of the largest and fastest growing minority groups in the United States. The 1990 Census enumerated 22.4 million Hispanics comprising about 9 percent of the Nation's total population. In the period between 1980 and 1990, the Hispanic population grew by 53 percent while the U.S. population grew by 10 percent (1). The literature reviewed in this paper indicates that Hispanics have a greater need for organ transplants and that they also have lower rates of organ donation. The size, growth, and relatively youthful age distribution of the Hispanic population, their socio-economic and linguistic characteristics, their medical needs, and their potential contributions to the organ transplant pool make the issue of Hispanic organ donation an appropriate and vital element of any effort to increase the levels of organ donation for transplantation. This paper shall focus on barriers to Hispanic donation and to the principles which might be applied to mount an effective campaign aimed at the Hispanic population.

### **Characteristics of the Hispanic Population**

Hispanics are an aggregation or agglomeration of several distinct national origin subgroups: Mexican, Puerto Rican, Cuban, Central and South American, and Other Hispanics. The term Latino has a growing preference over the use of the term Hispanic. To reflect this and still be consistent with those who continue to use Hispanic, I will use the terms interchangeably (2). The Mexican origin population is by far the largest Latino sub-group, constituting 62 percent of the United States' Hispanic population. The Puerto Rican, Central and South American, and Other Hispanics form a cluster of values at 13 percent, 11 percent, and 9 percent respectively. Cubans make up about 5 percent of the total Hispanic population (3). Among these different subgroups we can find a population variety of different genetic backgrounds, socio-economic characteristics, immigration or generational status, and geographic distributions. If any of these distinctions are pertinent to the specific subject at hand, then the subgroups will be referred to individually. There are also

many instances when Hispanics may or must be referred to as a group. There are many similarities among all or some of the Latino subgroups. Also, the amount known or written about Hispanics and organ donation is very scarce. The literature on this topic which distinguishes between the different subgroups is almost non-existent.

There are distinctive patterns of geographic distribution found among these subgroups. The Mexican origin subgroup is the largest Hispanic group in the Southwestern States and Illinois, Puerto Ricans outnumber other groups in the Northeastern States, and the Cuban origin Hispanics are the largest group in Florida. Large proportions of the Central and South American and Other Hispanics are found in Florida and the Northeast. The observation that large measures of the Hispanic population are concentrated in just a few States is confirmed by the percentages of the national Hispanic population in each State as well as by the cumulative percentages. One State, California, has about one-third of the nation's Hispanics. Three States combined -- California, Texas, and New York -- have about two-thirds of all Latinos in the U.S. Furthermore, the ten metropolitan areas with the largest Latino population contain about 62 percent of all Latinos. In descending order, these are: Los Angeles, New York, Miami, Chicago, San Francisco, Houston, San Antonio, Dallas/Fort Worth, San Diego, and El Paso (4).

Latinos are younger than the non-Latino population. In 1988, the median age for Latinos was less than 26 years; for non-Latinos the median was almost 33 years (5). The younger Latino age structure is reflected in the fact that the Latino proportion of the school age population in many areas exceeds the overall population proportion of Latinos. The higher concentration in younger age groups reflects higher fertility rates and the fact that many immigrants come to the U.S. during their child-bearing years. This demographic characteristic has several implications for an education and outreach program regarding organ donation. First, a program targeted toward youths could have long-term payoffs as these youths are exposed to circumstances over their life course requiring them to make a decision regarding organ donation. The preponderance of Latinos among the youth of many areas requires that a long-term educational program take account of their particular characteristics. The young Latino age structure also has another long-term implication -- as the entire population ages, a large part of the Anglo baby boom population now in their late thirties and early forties will eventually be concentrated in the age groups over 65 from which organ donations are not currently acceptable. The demographic future of the U.S. clearly has a large proportion of Latinos, African Americans, and other minorities in its future work-age population (6).

Many Hispanics are recent immigrants and immigration accounted for about half of the growth during the 1980s. While immigration is a major source of Hispanic population growth and many Hispanics are recent immigrants, many Hispanics are descendants of families which have been U.S. citizens for generations. The distinctions between

immigrant and native-born are often drawn in terms of generational differences. Typically, first generation refers to foreign-born immigrants with foreign-born parents; the second generation consists of a person born in the U.S. with one or two foreign-born parents; and the third generation consists of the U.S.-born children of U.S.-born parents. This last category includes all those who have been in this country for more than three generations as well and could be referred to as the third and third-plus generation. If Puerto Ricans born in the Commonwealth are counted as foreign-born, 58 percent of Latinos between the ages of 25 through 64 residing on the U.S. mainland were first generation; 17 percent were second generation; and, 25 percent were third generation. If the first and second generation are combined, 75 percent of the Hispanics had a direct, or through immigrant parents, indirect, contact with a foreign country, a foreign culture, and a foreign language (7).

The high proportion of immigrants among Latinos explains part of their lower attainment in education, income, and occupation. The poverty rate for Hispanic families was 23.4 percent in 1990, compared with 9.2 percent for non-Hispanic families. The median Hispanic family income was about two-thirds of the median income for non-Hispanics. The Latinos unemployment rate for 1990 was about 60 percent higher, and Hispanics that did have jobs were concentrated in unskilled and semi-skilled occupations (8). A similar report for 1988 showed that half (51 percent) of the adult Latinos had at least a high school education compared to 78 percent of all non-Latinos. The 10 percent of Latinos who had completed 4 or more years of college was about half of the non-Latino proportion of college graduates. Correspondingly, the Latino high school dropout rate was more than twice as high the non-Latino rate (9). Illiteracy is much higher among Hispanics than either Blacks or Anglos (White non-Hispanics) (10). A recent study projected that in 1991, 20 percent of the Spanish language population would be monolingual Spanish speakers, 37 percent would be Spanish-dominant bilinguals, and 43 percent would be English-dominant bilinguals. It appears that the amount of Hispanic immigration in the 1980s has greatly exceeded the level assumed in making these projections. Increased immigration would increase the Spanish-dominant and lower the English-dominant projected proportions. English monolingual Hispanics are not part of the Spanish language population (11).

Immigration, however, does not fully account for the lower attainment levels of Latinos. I have argued elsewhere that the recent historical experience of most second and third generation Hispanics contradicts the claim that they are achieving parity in measures of social or economic attainment with Anglos. There is not even a tendency in that direction. Instead, many educational and economic measures indicate that Latinos are not making progress and some even show relative and absolute declines even among those Hispanics who have been in the U.S. for a number of generations. The relatively small proportion of educationally and occupationally mobile Latinos has many social and cultural attributes of the majority Anglo population. However, there is a large number and proportion of second and third generation Latinos, many of

whom are English-dominant, who have lower income and educational levels and a diffident orientation to many elements of mainstream institutions (12).

### **Segmenting and Reaching Latinos**

The previous description of Latino characteristics and the literature cited imply that it would be useful to divide or segment the Latino population into three major groups. One consists of Spanish-dominant recent immigrants with lower class jobs. This group would be concentrated in cities that had experienced substantial immigration during the 1980s. Many Central American origin Latinos would fall into this category as well as a large number of Mexican immigrants. The second group is composed of English-dominant second, third, and third-plus generation adults with low educational levels and lower or working class occupations. The literature cited above suggests that Mexican Americans and Puerto Ricans would comprise most of this group and that it would be found in high concentrations in the Southwest and Northeast. The third group consists of an English-dominant middle class. This would be a relatively small group. The literature suggests that it would be geographically dispersed and that appeals or advertisements regarding organ donation that were targeted towards the U.S. population as a whole would also reach this group.

Currently, many advertisers believe that all Hispanics should be reached through Spanish language advertisements. The attention paid to the Spanish language population is a recent and well warranted recognition by advertisers of the size and nature of this group. Any health education and outreach program that did not address the Spanish-speaking population would miss a large group with extensive needs. However, not all Latinos are Spanish-dominant. The English-dominant lower and middle class groups have to be addressed as well. Spanish language media will reach some members of this group directly or, through family and friends, indirectly. Areas with large Latino populations may require an English language outreach campaign which targets this group as well. Hernandez and Newman outline elements of an English language campaign that may effectively reach the entire English-speaking audience. Their suggestion is to use an "ethnicized message" emphasizing Latino food, music, language, etc., in a context which will not disaffect the non-Latino audience. One example of this is using and pronouncing Spanish words or names with the correct Spanish pronunciation in an English language message. As another example, they mention a recent television commercial for McDonald's depicting a party for a young girl. To most viewers, the commercial simply depicts a birthday party; for some Hispanics, the commercial depicts or suggests a quincienera, traditional coming-of-age celebration (13). This approach takes advantage of the fact that many Latinos are English-dominant yet identify with elements of Latino culture and tradition. Common sense and empirical research both suggest that Hispanics are best reached in their native language, whether it be English or Spanish (14).

## **Hispanic Organ Transplantation and Donation**

It is surprising to find that there are very few epidemiological studies of Hispanic organ donation or transplantation. It is generally believed that Hispanics, as a group, have a higher rate of end-stage renal disease (ESRD), but this is usually supported by references to a careful study of ESRD in Mexican Americans conducted in San Antonio, Texas. Pugh and her colleagues find that Mexican Americans had an age-adjusted incidence of ESRD three times that of non-Hispanic Whites (15). Another study focusing on Los Angeles found that Hispanics had a slightly lower incidence of ESRD than Whites. Given the large concentration of young Hispanics in California and particularly in Los Angeles, the fact that this study did not make age-specific comparisons between Whites and Hispanics limits the applicability of its findings regarding Hispanic rates (16).

To the degree that the findings from San Antonio are generalizable to the Mexican American population as a whole, and the fact that Mexican Americans comprise 62 percent of all Latinos would tend to give all Hispanics a higher rate of ESRD if only because they dominate the composition of the aggregate group. In part, the high incidence of ESRD in Mexican Americans is tied to the higher incidence of diabetes in this group. The higher incidence of diabetes in Mexican Americans is a genetic heritage from Native Americans combined with the action of a strong environmental factor, presumably diet (17). The genetic heritage of Mexican Americans is probably similar to Central American Hispanics but different than that of Puerto Rican and Cuban Hispanics (18). African Americans also have markedly higher rates of ESRD than do Anglos. To the extent that the increased incidence of ESRD among African Americans is genetic, and to the extent that Puerto Rican and Cuban Hispanics share that genetic heritage, then these groups could also be expected to have higher rates of ESRD (19). At this point, the incidence and causes of ESRD among non-Mexican Hispanics is a matter of conjecture and speculation rather than fact. The statement regarding the genetic component of ESRD in African Americans and Caribbean Latinos should be read as a suggestion for future research on ESRD among Hispanics.

Another area in which the different genetic backgrounds of the Latino subgroups becomes important is that of the distribution of antigens. Whites, Blacks, Native Americans, and Asians have different distributions of ABO [blood group], MHC [major histocompatibility complex] and other antigens (20). To the degree that the antigens among the Latino subgroups reflect their different genetic backgrounds, this could limit the likelihood that organs from different subgroups would match. However, given these differences in the distribution of antigens, it is still possible to match and successfully transplant organs between Hispanics and Anglos. A sample of Hispanics in San Antonio, presumably Mexican Americans, were found to have a much higher rate of transplant survival than Caucasians whether the cadaveric donor was Hispanic or Caucasian. The survival rate of Caucasian kidney

transplants also was not dependent on the ethnicity of the donor. The survival rate of a Caucasian transplant was the same whether the donor was Caucasian or Hispanic. In both cases, the Caucasian survival rates were lower than Hispanic rates regardless of the ethnicity of the donor (21). A similar study of renal transplant survival rates in Caribbean Hispanics found that they also had significantly higher graft survival rates than the North Americans (22).

Kidney transplants are, by far, the most common transplant. However, the frequency of transplantation of other organs is increasing (3). The examination of causes of death might indicate if these advancing technologies have a different impact on Latinos than Anglos. The most prevalent cause of death among Anglos in California was heart disease; the fifth most prevalent cause was chronic obstructive pulmonary disease; and, the seventh was chronic liver disease. Among Mexican origin Latinos heart disease was also the most prevalent cause of death, and cirrhosis and liver disease was the seventh most prevalent cause of death (24). To the degree that death by these causes could potentially have been prevented or deferred by heart, lung, or liver transplants, the crude comparison suggests that Anglos might benefit more from the growth of the transplantation of these organs than would Latinos (25). The information necessary to present a similar comparison among the different Latino subgroups is not available.

Most of the evidence that the rate of Latino organ donation is lower than that of the Anglo population consists of comparing the proportion of Latino donors to the proportion of Latinos in the service area. Such comparisons do not control for differences in age distribution or causes of death, but the differences between the donor and population proportions are often so large that these comparisons probably do not indicate a lower incidence of Latino donation. For example, 52 percent of San Antonio's population is Latino; 80 percent of organ recipients there are also Latino, but Latinos are only 14 percent of organ donors (26). A very informative study of family refusal rates in New York, Miami, and Los Angeles shows that Latinos in all three metropolitan areas have much higher family refusal rates than Anglos. Each of these cities has a predominant concentration of a different major Latino subgroup suggesting that a disinclination to donate may be commonly found among all Latinos (27).

Another issue which remains unresolved is whether Latinos have the same chance of getting a transplant as an Anglo. Several studies have shown that Blacks do have a smaller probability of being the recipients of an organ transplantation even though they experience a much higher incidence of ESRD than Anglos. The lower proportion of minority donors does decrease the probability of matching blood groups and antigens. Several of the studies showing that Blacks have a smaller probability of receiving a kidney transplant also found the same to be true for non-White races. However, none of these studies specified if Hispanics were included in the data for non-White races (28).

Comparing the proportion of Hispanics who have received transplants to those on the waiting lists provides some evidence regarding the probability of Latino transplants. This comparison shows that the proportion of Hispanics receiving transplants was within 2 percent of the proportion of those on the waiting list for four major metropolitan areas. In two cases the transplant proportions were 2 percentage points greater than the waiting list proportions and in two cases the transplantation percentages were 2 percent less than the waiting list. The similarity of the proportions and the existence of positive and negative differences suggest that Latinos are getting transplantations in relation to their frequency on the waiting list. The pattern is very different for African Americans. While they represent a large proportion of the transplant waiting list, the percent of transplants is between 5 to 12 percent less than the proportion on the waiting lists in the same four metropolitan areas (29). While suggestive, this comparison does not control for the availability of matched organs. Moreover, the waiting list does not necessarily reflect the population that could potentially benefit from transplantation. Both individual and institutional factors could limit the placement of minorities on the waiting list (30).

An important element of any appeal for increased organ donation among Latinos is the claim that Latinos have a fair chance of getting an organ transplant if they should need it. This claim is supported by the similarity of proportion of Latinos having received transplants and on waiting lists and the fact that many Latinos receive organs donated by Anglos. However, the unambiguous demonstration of this point would only help an outreach campaign. If careful examination shows that equality of access is not currently the case, the adoption of this goal should be considered as part of the campaign.

### **Barriers to Hispanic Access to the Health Care System**

Hispanics have much less access to health care providers and institutions than any other group in the United States. The factors which limit access are lower rates of coverage by private or public health insurance, lower income levels, language differences, and scarcity of Hispanic health providers.

Much higher proportions of Hispanics are not covered by health insurance than those found among the U.S. population as a whole, or White non-Hispanics in particular. Only 10 percent of the White non-Hispanic population does not have either public or private insurance coverage compared to 37 percent of the Mexican Americans, 20 percent of the Cuban Americans, 20 percent of the African Americans, and 15 percent of the Puerto Ricans. Comparing Hispanics without insurance coverage to those with coverage shows that a much smaller proportion of those without insurance had a regular source of care and reported themselves to



be in excellent or very good health. Conversely, higher proportions of uninsured Hispanics reported never having had a routine physical examination or having seen a physician in the previous year (31).

These results confirm an earlier study which found that insurance and financial considerations were important factors in the number of physician visits by Latino children. In contrast, health perceptions were important determinants of physician utilization by Anglo children (32). A tabulation of responses from the Hispanic Health and Nutrition Examination Survey (HHANES) showed that by far the most prevalent cause of dissatisfaction with access to health care was that it was "too expensive." Other important factors were that the wait for an appointment was too long, the wait in the office was too long, and the long wait would cause loss of work and pay (33). Financial and insurance status and related factors create barriers to health care access by Hispanics. The characteristics of low income and high poverty levels of the Latino population discussed earlier corroborate the salience of these factors. These barriers are most conspicuous among the largest Latino subgroup, Mexican Americans.

Another set of factors creating barriers to health care have a social, cultural, or linguistic basis. Hispanics are extremely underrepresented among health care professionals and this is a cause of some of the problems Latinos have in getting access to health care (34). The ratio between the Latino population and Latino health care providers for California Latinos was more than ten times greater than the population-to-provider ratio for the total population (35).

Some have argued that cultural factors, particularly the utilization of, or credence in, the efficacy of curanderos, herbalistas, or other practitioners of folk medicine were obstacles to the utilization of health services by Latinos in the United States. A recent communication in JAMA even suggested that such practices and beliefs were factors in the lower proportion of Latinos donating organs for transplantation (36). However, only 4.2 percent of the Mexican American respondents in the HHANES data had been treated by a practitioner of traditional rather than scientific techniques. Furthermore, the utilization pattern of medical practitioners by the clients of curanderos was indistinguishable from that of the Latinos who did not use the services of the traditional healers. These facts suggest that the reliance on traditional medicine is not a major obstacle to the use of medical services.

A much more prevalent "cultural" factor which may well generate barriers to health care access is the existence of a large proportion of Spanish-dominant Latinos. The use of, or preference for, Spanish has often been used as an indicator of an attachment or fidelity to traditional culture. However, the Spanish-dominant individual, who represents a large proportion of Latinos, will also be less able to function well in English-dominant medical establishments which have, as noted above, an extreme scarcity of Latino professionals. A cogent article examining this

issue concludes: "[A]bility to speak English increases the extent to which Hispanics can effectively attain institutional access...In sum, regardless of one's level of acculturation on psychological or social dimensions, variation in language preference seems to be a critical determinant of utilization of health services, and is best viewed in terms of accessibility." (37)

A report evaluating methods to expand the number of organ and tissue donors offered three hypotheses to account for the low rate of minority donation: 1) donations may be deterred by cultural elements; 2) donations may be inhibited by socio-political dissension; or 3) health professionals may be reluctant to approach minority families (38). This brief discussion of barriers to better health access for Latinos suggests that the cultural element of belief in traditional medicine is probably not a major factor. Clearly, there are economic constraints to equitable access to the health care system by Latinos as indicated by the prevalent concern with health care costs and lack of insurance coverage. The reluctance to donate organs may in part have an economic component; in some cases, the cost of embalming an organ donor is raised by \$200. The lower rate of insurance coverage among Latinos may also limit the real availability of transplants. The amount of all kidney transplantation costs paid by Medicaid coverage varies from State to State (39). The third hypothesis, the reluctance of physicians to approach minorities, could well be, insofar as it refers to Latinos, the flip side of accessibility limited by language. It could be postulated that economic or linguistic barriers might translate into social or political conflict, thus supporting the second hypothesis, and this might indeed be a factor inhibiting Latino organ donation. However, none of the material reviewed provides direct evidence of social or political conflict. It is simpler and more direct to propose a fourth hypothesis: i.e., economic, insurance status, and linguistic factors create barriers to the complete integration of Latinos into the health care system and these factors directly and, through the consequent decrease in integration, indirectly contribute to the lower rate of organ donation.

### **Hispanic Attitudes Towards Organ Donation**

The amount of information available on Hispanic attitudes towards organ transplantation was greatly increased by the survey of Hispanic households in northern California conducted by The Gallup Organization for Dr. Oscar Salvatierra and his colleagues with the Organ Procurement Organization Transplant Service at the University of California, San Francisco. The survey consisted of telephone interviews of 505 Hispanic household heads conducted early in 1987. The survey questionnaire was designed to measure and evaluate Hispanics' knowledge of and attitudes towards organ donation and related issues.

While 82 percent of the sample felt that they were treated fairly when they go to a hospital, clinic, or doctor, only 68 percent of the foreign-born respondents, 70

percent of the Spanish-dominant respondents, 72 percent of the low income respondents, and 74 percent of the respondents with less than a high school education felt that they were treated fairly. These characteristics are all associated and point to the characteristics of the Hispanics who are going to have the least access to, and be the least integrated with, the health care system. The response to two related questions also indicates a lack of trust in the system and physicians. More than half of the respondents, 55 percent, stated that the belief that "They might do something to me before I am really dead," was a very important (42 percent) or somewhat important (13 percent) reason for not giving permission for organ donation. The second very closely related question indicates who "they" are. The fear that doctors might hasten their death was given as a very important or somewhat important reason for not agreeing to be organ donors by 54 percent of the respondents. Compared to the responses to the same question on a 1984 poll of the U.S. population as a whole, the Hispanics' responses indicating that these fears are factors in the decision not to donate are much higher. They are also sentiments that connect the lack of access and integration with the unwillingness to donate organs.

Most Hispanics, 87 percent, are aware of organ donation and transplantation. Again, the lowest proportions of respondents with awareness of the procedures were found among the lowest income group, 77 percent, and those who were either foreign-born or had less than a high school education, 81 percent of each category. The level of awareness for the U.S. population as a whole in 1984 was 95 percent. Education and outreach could contribute to changing this for all Hispanics, especially for foreign-born, Spanish-speaking, and less well educated Hispanics. Two other elements that should be part of a public education campaign are the fact that Hispanics do have a greater need for organ transplants than non-Hispanics; and, the fact, if it is indeed true, that Hispanics do get their fair share of donated organs. Only 3 percent of the survey respondents thought that Hispanics had a greater need for donated organs and only 28 percent thought that Hispanics got their fair share of organs. On this second issue of equity, 54 percent were not sure that Hispanics did get a fair share. Given the uncertainty on this issue in the professional literature, resolving this point and advertising an affirmative finding would fill a knowledge gap regarding organ transplantation and could influence Latinos' willingness to participate in organ donation.

Another survey response indicates what might be an important justification for, and element of, a public education campaign targeted at Hispanics. Half of the respondents said that the fact that they had never really thought about organ donation was an important reason for not participating in organ donation. This was a higher proportion than in the U.S. population generally.

Religious considerations played a smaller role as an expressed sentiment against donation than the issues discussed above. Only 34 percent of the Latino

respondents said that the belief that organ donation was against their religion was a reason for not donating. Only 8 percent said that their religion forbade donation, but 24 percent did not answer or were not sure. About a third of the respondents listed concerns about having their body intact for resurrection or an afterlife as reasons for not donating organs. The religion-oriented objections are not a factor for a majority of Hispanics, but the proportion of Hispanics who list such responses is greater than for the general U.S. population. This indicates that religious objections are not a major factor among Hispanics but they are relatively more important than for the U.S. population as a whole. Another possible indicator of an orientation towards religious issues was that a priest was third on the list of persons respondents would feel most comfortable talking to about organ donation. The top two choices would be a relative or a doctor.

This survey has additional important information on Latino attitudes towards organ transplantation, including information related to approaching the next of kin and media use. The findings will be discussed in the following sections.

### **Approaching the Next of Kin**

A recent study evaluating methods for increasing organ donation found that the education of the personnel who would approach the next of kin and request permission to retrieve the organs was more effective if it focused on methods for approaching grieving families rather than on technical information (40).

The California Transplant Donor Network has used the results of the San Francisco survey to compile procedures for approaching the next of kin. It can be read as a protocol for approaching families which responds to the suggestions of the evaluation report above. I will briefly summarize it here:

The physician should inform the family of the death of the patient. The concept of "brain death" should not be introduced because it seems to mitigate the finality of the declaration. The request for permission to retrieve organs should be separated from the pronouncement of death and the approach made by a transplant coordinator. The next of kin may want to defer to an elder member of the family in making the final decision. The discussion should include important relatives, English-speaking friends, and a priest. However, it may be advisable to keep the number of people involved to a minimum. The content of the discussion should emphasize the routine nature of the request and the fact that the family might be comforted by knowing that the donation is a gift. Concerns that the survey respondents commonly raised can be allayed by emphasizing that the request is initiated only after the patient is dead; that it is simple to give permission; that the donation can be done confidentially if there is concern that other family

members will object; that most religions, including Catholicism and Protestantism, support donation; and that the procurement procedure is done like other surgery -- the corpse is not simply cut up. The transplant coordinator would preferably be completely fluent in English and Spanish. This individual should remember that many Hispanics prefer to speak English and that some may not be literate (41).

The use of this protocol or one like it could be the basis for starting and maintaining an ongoing evaluation of the different aspects of the organ donation process.

### **Reaching the Hispanic Population**

A public education campaign focused on Latinos should mention that this group has a greater need for kidney donations, that the costs of kidney transplants are covered by Medicare, that there may be associated costs which are not covered, and that Latinos receive their fair share of organ transplants, if further research shows that this is indeed the case. These aspects of organ donation should be mentioned in a context which provides general information about organ donation and transplantation. However, there is another desirable element of a public education campaign -- it should evoke a response whereby members of the audience tell family members that they would like to have their organs donated if they should die in a manner where this is appropriate. The proportion of survey respondents who said that they would give permission for organ donation increased from 54 percent in the case where the respondent had not discussed this issue with the decedent to 94 percent in the cases where the decedent had explicitly expressed a desire to donate organs (42).

One way to make an appeal with this goal in mind would be a family-oriented television show. One example of how this might be done with reference to the Spanish-dominant segment of Hispanics is to place an articulate spokesperson on Sabado Gigante. This is a very popular Spanish language variety show broadcast for 4 hours every Saturday night. The show includes music, contests, games, and at least one segment devoted to a serious, educational topic. A discussion of the importance of organ donation to Latinos seems like an appropriate topic for such a segment. A well-constructed campaign could include an appeal (on this or a similar program) to tell a relative about the desire to donate organs.

The research literature on Latino media use is similar to that on Latino epidemiology or demographics: too often it consists of small-scale local studies from which it is difficult or dangerous to generalize. In addition, studies of media use are even less useful now due to recent changes in Latino immigration and

because they do not present the information necessary to segment or stratify the Latino population in terms of nativity, language dominance, national origin, or class.

Other means of achieving the same goals could include using Spanish and English radio and television public service announcements and organ donation themes in popular television shows, particularly soap operas or novellas, which would emphasize the importance of discussing organ donation with family members (43). The use of different media in different languages will reach different segments of the Latino population. For example, the audience that prefers Spanish language radio differs from the Hispanic audience of English language radio in the following ways: they prefer Spanish television, they prefer speaking Spanish at home, they are less educated, older, listen to the radio during the morning and midday, buy more records, tapes, and soft drinks, and are more likely to be married (44). While none of these characteristics have a conspicuous association with organ transplantation, this type of information could be the start of a knowledge base for effectively educating different segments of the Latino audience on an individual basis. Since it is true that, "Anheuser-Busch pitches differently to Hispanics in Texas and California," a health education campaign probably would be well-advised to follow the same principles (45).

Another way to reach the Latino population is with the cooperation of various non-profit groups or community-based organizations with good connections to various segments of the Latino community.

#### Conclusion: Would an Outreach Campaign Targeting Latinos be Effective or Divisive

Some of my suggestions regarding the components of a campaign to increase Latino organ donation could be seen as divisive. If Latinos do have a higher need for organ transplants, this fact might diminish the willingness of non-Latinos to donate. If it became known that Hispanics are receiving their fair share of organs but African Americans are not, then this too might create inter-group friction rather than cooperation. Since any campaign to increase organ donation will focus increased attention on the subject of equity, it is best to confront the issue directly. Inter-racial equity of transplantation has been a major concern in the scientific literature. Any increase in the attention given to transplantation, whether it specifically focuses on minority donors or not, will call attention to the issues of equity and fairness. The reason to focus on minority donation is because it represents a large group of potential donors who are currently under-represented. The way in which the equity issue should be addressed is to make equity of transplantation and donation for all groups a strongly desired goal. A campaign targeting Hispanics would not be an effort to treat this group differently, but to

recognize their differences so that they may participate equally. Ignoring current inequities will not encourage the minorities who are not completely participating to change their behavior. I suggest that efforts to improve the rate of organ donation adopt two related goals. The first is to develop the information resources necessary to evaluate and monitor the inter-racial equity of organ transplantation. The second goal is to make the attainment of equity a top priority. A commitment and effort of this nature would provide a welcome and appropriate encouragement for minorities to fully participate in the organ transplantation system as recipients and as donors.

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